Witness Name: GRO-B
Statement No.: **WITN0054001**
Exhibits: **Nil**
Dated: 24 July 2019

## INFECTED BLOOD INQUIRY

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## WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 May 2019.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My is GRO-B My date of birth is GRO-B 1963 and my address is known to the Inquiry. I am a business owner, and I currently live in the USA with my wife.

2. I have severe Type A haemophilia. I intend to speak about my life after contracting Hepatitis C ("HCV"), Hepatitis B ("HBV") and HIV from using blood products in the UK. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment received and the impact it has had on me and my family.

3. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement.

4. My brother (GRO-B) has also provided a witness statement to the Inquiry.

## Section 2. How Infected

5. My brother (he is older than me) was diagnosed as having severe haemophilia A after he didn't stop bleeding following circumcision soon after his birth. Therefore, when I was born my parents knew to test me for haemophilia. I was subsequently also diagnosed as having haemophilia A, just like my brother. My mother is the carrier for haemophilia; she had nine brothers and sisters, but none of them had haemophilia.

6. My family moved to the UK in the late 1970s. We moved to the UK partly because of my Dad's business, but I think the main reasons for moving our family to the UK was so my brother and I could access better medical treatment.

7. I recall that when we arrived in the UK I was basically admitted to the local hospital immediately for a bleed in my left knee, a joint that caused me most issues. I believe I was given cryoprecipitate to treat my knee. I recall developing a reaction to the cryoprecipitate, I remember shaking. I was grateful to be treated as I was almost crippled at the time. In childhood I would have hallucinations from the pain, so I was grateful that there was a new treatment available.

8. My GP at the time didn't treat haemophilia so referred me to a hospital in London. That's when I started taking Factor VIII. I was never told of any risks or issues associated with using Factor VIII. I definitely wasn't told that there was a risk of being infected with a virus. I was told Factor VIII was safe and later on was told that it was heat-treated. I recall life being easier once I started using Factor VIII as I didn't have to take as much time off school.

9. I would go to the hospital in London once a month and I would be given Factor VIII to bring home and use. It had to be kept in the refrigerator and came in a narrow brown box with 10 vials to a box. I remember there were three different brands that I was given; I remember taking Cutter and Armour products. Then you had to mix it with water. I wasn't actually taking that much Factor VIII, I recall it was expensive.

10. In the early 1980s my father moved his business to the USA. I followed my father and moved to the US in 1983 or 84. When I moved to the USA, I attended a local hospital to receive treatment for haemophilia.

## HIV

11. In 1987 HIV was all over the media. I believe there was a HIV test available in 1984 or 85 and I think I was offered to be tested then, but I declined to be tested. I don't know exactly why I declined, but I think it was because I knew of the ramifications and stigma surrounding HIV, and I was afraid and just wasn't ready. My brother was diagnosed with HIV a few years earlier, and I witnessed the problems he was going through, both medically and personally.

12. Prior to my HIV diagnosis my health was suffering generally; I had no appetite and diarrhea. I didn't feel like doing anything and found it difficult to attend college. I lost interest in life and was feeling depressed. Before I was tested for HIV I had been thinking about whether I had it.

13. The haematologist who I saw at the local hospital wanted me to be tested for HIV. So, in 1987 I underwent the test, and unfortunately the result came back positive. Although it wasn't a shock, I still found the diagnosis difficult to cope with.

14. When I was informed of my diagnosis I was told about the risks and what precautions to take. I was also told to see a social worker at the hospital every month where I was also informed about transmission risks.

15. I am one hundred percent sure I got HIV from Factor VIII. I had never exposed myself to risk groups, never took drugs and I never had a girlfriend in the UK.

HCV

16. In 1991 or 1992 I was tested for HCV. It was the same doctor who treated me for HIV who wanted to know whether I had it. I didn't think the test was necessary at the time as I was focused on my HIV progress, but I underwent the test. My result came back positive.

HBV

17. I knew about being HBV positive while I was still living in the UK. I had an emergency medical card which had 'Hepatitis B positive' handwritten in blue ink. I never had any conversations about it. I did ask doctors what it meant but my questions were either side-lined or ignored so I didn't really focus on it either.

18. I think I might still have HBV. HCV was the more difficult to treat disease that doctors were worried about, so I think they just focused on that. I think perhaps staff at the time weren't trained, but it's hard to say. No one has spoken to me about HBV, not even in the US, but I believe I should have been told about being tested for it, being diagnosed with it and the risks associated.

## Section 3. Other Infections

19. To my knowledge I have not received any other infection, other than HIV, HCV and HBV, as a result of being given infected blood.

## Section 4. Consent

20. In the US I was tested for the viruses with consent. For a period I would also donate blood with consent to give to the CDC for testing.

21. In the UK doctors would routinely take blood when I was in hospital and I wouldn't really ask why. I recall being told at one stage about having an inhibitor. I don't know if I was tested for other viruses while I was in the UK, I definitely wasn't told if I was.

## Section 5. Impact

### HIV treatment

22. I was initially treated with AZT, which was previously used as a chemotherapy drug. It made me throw up, feel nauseous and I couldn't focus.

23. Following my HIV diagnosis I experienced a series of health issues. Around 1988-1989 I began losing weight; I weighed just 130lb which is significantly below what I should weigh at my height. In 1989-1990 I was diagnosed with cryptosporidium, which is an infection of the intestines. I also had lung infections where I needed a compressor pump and tubing in my mouth and antibiotics. My T-cell count was also low and my liver was not doing well.

24. When a new class of drugs came on the scene, I was taken off AZT and my appetite came back. I also had a better outlook on life and was feeling more positive. When taking AZT my T-cell count was only at 87, but when I started to try other drugs my count started going up slowly. I am now up to around the 400 range, so almost at the normal range for a T-cell count.

25. Since 1987 I have been prescribed a series of HIV drugs. To date I have taken 14 different medications, each with their own different side-effects:
    a. AZT – nauseous and vomiting;
    b. Didanosine ("ddl") - this was a chewable pill which destroyed at least 6 of my upper and lower teeth. I spent a fortune fixing my teeth after taking this drug. I also tried a liquid version of ddl;
    c. Norvir – caused gastrointestinal issues including stomach pain and diarrhoea;
    d. Invirase – caused headaches;
    e. Sustiva – caused headaches;

f. Truvada – caused nightmares;
g. Videx; none
h. Epivir – caused headaches and confusion;
i. Epzicom; none
j. Biktarvy – I only took this medication briefly as it affected my heartbeat. I was told by doctors to quit caffeine, but I knew it was the medication causing the issue;
k. Prezcobix; none
l. Reyataz. None
m. Juluca. None

26. As I have progressed through the medications over the years I slowly re-gained weight. The medications have worked, but the side-effects have been difficult to pin-point. I have had trouble sleeping, headaches and trouble walking at times. Arthritis also kicked in, which I don't think was caused by haemophilia. I've experienced loss of memory, confusion, anxiety and panic attacks. My wife believes my personality has changed, but I'm not sure if it's just the fear of the unknown and anger that this has happened to me.

27. I am currently taking a medication called 'Juluca' to treat my HIV. I take one pill per day. When I first started taking this medication I was experiencing nightmares. If I watched a movie, it would come back as a vivid dream. But this side-effect is not as frequent now.

28. I have been undetectable for HIV for 15 to 18 years now. I fear the virus is lying dormant in my brain or bone marrow. The medications work but as soon as you skip doses, the viral load goes up. I had severe food poisoning a year or so ago so I stopped taking my medication because I physically couldn't swallow the pills. By not taking my medication my viral load went up and the doctor was quite upset with me.

29. In the past doctors have told me that I would eventually become immune to 'full-blown' AIDS and my body would fight off the infection. I was also given this information from my doctors in the UK when I called to speak to them. Although I now think that the doctors just weren't sure how HIV and AIDS worked and didn't know how to deal with it.

HCV treatment

30. Following my diagnosis with HCV, my doctor went over the treatment options available and the only one was Alpha Interferon subcutaneous injections. I started this treatment in 1993.

31. I understood the treatment wasn't going to be easy; my doctor told me many people stopped the treatment, but I wanted to worry less about HCV so was determined to complete the course of treatment. I experienced devastating side-effects including bone pain (which was different to the arthritis from haemophilia), my appetite was suppressed, I had extreme migraines and headaches and mood swings. I had mood swings, was angry and hated everything, I became more argumentative, I was like 'Dr Jekyll and Mr Hyde'.

32. After 6 months of taking Interferon I was cleared of HCV.

33. The Interferon medication removes the virus from blood but the damage that has already occurred remains and the liver doesn't regenerate. My liver is still damaged to this day and I have cirrhosis. I also have fatty liver disease which doctors are not sure if it is hereditary or caused by HCV. I think it has been caused by the combination of HIV and HCV medication. I undergo fibro scans every 6 months.

Continuing medical impact

34. I am currently clear of HCV. I am undetectable for HIV, however, treating HIV is a continuous and complicated process. At this stage I am stable, but at the beginning it was very up and down.

35. I have abnormal counts for my kidneys. I understand the antiviral medications do something to harm the kidneys as they filter the medications.

36. I also experience memory loss which is attributable to having had HCV.

37. I take natural medications and supplements such as Echinacea, Goldenseal and Milk thistle in liquid form. I think this works and has triggered something in my immune system; I will try anything to help improve my health.

38. My brother is going to start taking a new drug to treat haemophilia, but I have decided that I will hold off for a year before I try it as I am not sure of the side-effects.

Mental impact

39. After my HIV diagnosis, the Infectious Disease specialist offered me antidepressants but I only took them for one month. I found being on antidepressants too intense and I was afraid I would become addicted. I didn't want to have to deal with another medical issue.

Family

40. I have been married twice. I believe taking medication for HCV and HIV caused the main issues with my first marriage. The medication, especially Interferon, affected my mood and I became angry person and couldn't tolerate people. We attended marriage counselling, and the marriage counsellor was someone who frequently dealt with HIV patients, usually from the LGBT community. Unfortunately the marriage did not last, and we divorced.

41. I have been married to my current wife since 2006. Although she understands my medical conditions, and has done from day one, she is facing more difficulty in accepting my illness. My wife has OCD and is obsessed with cleanliness so is becoming more concerned about us interacting including sharing cutlery and even kissing. It is having a devastating effect on our relationship. I have suggested my wife see my doctor but she refused. We now have very minimal interaction and it is like living with a friend. My wife has been tested for HIV in the past to which the results were negative.

## Immigration

42. When I went through immigration proceedings to become a US citizen, I almost faced deportation because of my HIV positive status.

43. I found a lawyer who was willing to assist my case. My lawyer convinced my first wife to marry me to assist my application and prevent my deportation. My parents weren't happy about me getting married under these circumstances, but it was a legitimate marriage and there was love. It is unfortunate that the marriage didn't last.

44. My lawyer also found a waiver to allow people who have a positive HIV status to remain in the USA. I'm glad I have been able to stay in the USA and afterall I was medically harmed by product that was possibly made in the US. Immigration law is very complicated and it was a very lengthy and stressful process. I have been a citizen of the USA since 2003.

## Education and work

45. I wanted to do my Masters in the UK, but at the time my health was suffering. I applied to many colleges in the UK. I recall attending an interview with a professor and my dad was also with me. It was a successful interview, but as soon as the professor found out I had haemophilia, he changed his mind about letting me in. I was given an excuse about them being concerned I couldn't handle walking up flights of steps. There was an ignorance about haemophilia, I can just imagine what would have happened if I'd known and told them about having HIV.

46. Soon afterwards, my father moved to the USA, so I also moved and pursued my education there.

47. I was taking AZT during the time I was doing my Masters in Chemistry which was having an impact on my performance. I was struggling to concentrate and feeling sick generally.

48. I completed my Doctorate in Chemistry in 1993. I starting looking for work soon afterwards but as soon as potential employees found out about my haemophilia I wouldn't get a call back.

49. In 1994 I worked in a laboratory as a lab technician for about 6-7 months. This job involved a commute of almost 3 hours there and back. I also found it very hard to stand all day and found myself having to treat with factor every day. One day I had a serious driving accident and was almost killed, this proved to me that I wasn't able to continue this job as I wasn't able to focus.

50. I found it difficult to try to find another job. My dad had a friend who needed help in business, so I moved to office work the year later. From 1997 until my father's passing, I worked for his business. My brother and I have continued to run my father's business, and while it is very slow at the moment, at this point I don't think I could get another job. A few years ago I tried looking into other work opportunities but had no luck.

51. My ultimate goal was to be a doctor of medicine or working in the pharmaceutical industry, but my HIV infection always prevented me from doing this. At the time it was general knowledge that I couldn't work in the medical industry because of the risk factors of having HIV.

## Stigma

52. I don't really have any friends because as soon as they know I'm haemophiliac they turn and go the other way; people act as if there is something wrong with you. It's very hard to explain, but being a haemophiliac is immediately linked to having HIV. In the past, a couple of people have asked me if I have HIV because I have haemophilia. People would see stories in the news and were curious, but then if they found out I was haemophiliac, they would react to me differently by talking to me less and shunning me away.

## Section 6. Treatment/Care/Support

53. I was offered one-to-one counselling on being diagnosed with HIV; however, I never went. Counselling is something that I might consider soon as I am finding it all hard to deal with at the moment.

54. When I was first diagnosed with HIV I was required to meet regularly with a social worker from the hospital. The social worker also met with my first wife to explain chances of infection. The social worker even went as far to tell my wife to leave me. I feel they tried their best to separate us. I think medical professionals at the time felt under pressure from the CDC to separate couples. At the time I was hurt but now I can see that they were just trying to do their job.

55. For a while I attended a support group for haemophiliacs with HIV, but then stopped attending when my HIV started becoming undetectable.

56. Factor VIII was life changing so my brother and I took it. I had no clue that years later it would cause me such severe health problems. Doctors never mentioned or explained any risk associated with Factor VIII. I think the NHS was just giving me whatever brand was available, but I have a gut feeling that it was the Armour product that gave me HIV. I took Armour Factor VIII for the longest period, maybe up to 2 years in duration. It was only when I was doing research later that I started to suspect it was Armour that was the cause of my HIV and HCV infection. Years later, I read newspaper articles about blood products coming from prisons and sold to the UK.

57. A dentist in New Jersey refused to treat me at his private clinic, when he found out about my HIV status, this was in 1990 or so. I needed a tooth extraction at a hospital in Newark, NJ. the surgery was done there, the doctor was the attending professor there at the time and would only supervise my operation.

## Section 7. Financial Assistance

Medical insurance

58. I have not had trouble accessing medical assistance, but as I live in the USA, I require private medical insurance to afford medication. I pay a monthly premium of over $400 USD per month. Under the last government I could access 'Obamacare' which meant that I didn't have to pay any insurance premium, but this has been cancelled, and under the new administration you need to have private insurance.

59. My insurance covers the cost of my factor prophylactic for haemophilia, but this means my premium is very high.

60. My HIV medication costs almost $3000 USD per month. The insurance company pays 80 percent of the cost and I have to pay for the rest ($600). I find it very difficult to cover the cost of the medication and my medical debt currently stands at around $2-3000 USD. I am receiving letters from the lawyers for the pharmaceutical companies chasing me for money. If you aren't able to afford the medication and your debt builds, then you can face the cancelation of medical insurance. I am trying to resolve it somehow, and hopefully will be able to come to an agreement to pay in instalments.

61. It is a very complicated and difficult system to navigate. It makes me afraid for the future, afraid that one day I will be cut off and won't have access to factor product or antiviral medication.

Schemes

62. I first heard about the Macfarlane Trust from my doctor in London. I think I had called him, requesting paperwork or something like that, and he mentioned to me that there was special assistance available. He sent me the form in the mail for me to complete. I am unable to recall when I first started receiving a payment from the Macfarlane Trust but I now receive £1500 per month.

63. I was aware of the Skipton Fund by a worker at the MacFarlane Trust in London, they sent me the forms. The year was around 2006. I received the Stage 1 payment of £20,000 from the Skipton Fund. I was refused the Stage 2 payment as they said my liver wasn't damaged. In response I sent them my blood work, but I was still not accepted. I receive £1500 per month from Skipton.

64. EIBSS has now taken over the management of Macfarlane and Skipton, but now I feel I am treated as a number rather than a person. I was required to fill out a couple of forms for EIBSS, basically covering the same process all over again but this time I didn't have to get a doctor's signature.

65. Initially the Macfarlane trust provided a more personal service, but found that they became more and more indifferent to my requests as time passed. I was denied many grant requests by the MacFarlane Trust the few years before the NHS took over and had to appeal their decisions a few times. My e-mails were being ignored too, not only was I dealing with a difficult financial situation and two diseases (HIV and Hep C) but also with people who were entrusted with the difficult task of making our lives worthy. They just didn't care for us.

## Section 8. Other Issues

66. It is very hard to go back in time to look at what has happened. I just want to leave all the negative thoughts and stressful events behind me. I look at this as an event that no one predicted and I'm not sure if anyone can be blamed for it.

67. I have lost many friends from HIV, I consider myself very lucky to have access to medication.

## Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-B

Dated July 24th 2019